

## Royal College of Nursing Evidence to the All-Party Parliamentary Group (APPG) for terminal Illness Inquiry into Legal Definition of Terminal Illness

Thank you for inviting the Royal College of Nursing to respond to the above inquiry.

### Introduction

The Royal College of Nursing (RCN) is the professional body and union for the Nursing Profession. Our members represent Nurses from across the workforce including those who work with people who have terminal and/or long term degenerating conditions and those requiring palliative care.

As an organisation, the RCN has been involved in a number of campaigns to review the current benefits system for people with who are dying and those with fluctuating, deteriorating and debilitating conditions such as Motor Neurone Disease and in particular those who are living with dementia. The RCN is a partner in the Continuing Care Coalition seeking reforms of the current Continuing Healthcare funding. In addition, the TUC and other trades unions including the RCN are campaigning for terminal conditions to be made a “protected characteristic”, meaning that employees facing the end of life should not be dismissed because of their condition which puts further stress and pressures on dying people and those that they love <https://www.dyingtowork.co.uk/>

The TUC and other trades unions including the RCN are campaigning for terminal conditions to be made a “protected characteristic”, meaning that employees diagnosed with a terminal illness or condition should not be dismissed from their employment because of their condition <https://www.dyingtowork.co.uk/>

The RCN's Membership Department supports nurses who are themselves ill and living with life limiting illnesses. We have included in our response on some of the information these members have provided us with which we hope will be of interest to the APPG in its inquiry.

### Key Messages

1. The current definition of terminal illness being six-months is no longer fit for purpose particularly in the way that support, especially financial support, is offered to patients. As the APPG may know, many people wait inordinately long periods of time for benefits because they do not meet the current requirements leaving them living with significant hardship.
2. While the RCN accepts that the approach recently taken in Scotland is superior to that in England we would be concerned that a wholesale adoption of the Scottish approach would
  - I. effectively remove the current fast-track process and
  - II. place responsibility on the medical profession to provide the DWP with very detailed reports on care and mobility needs of the individual.
3. The RCN position is that future systems/processes refer to **life limiting illnesses** and/or **debilitative illness** rather than terminal **illness**. Additionally the RCN would assert that access to financial support is not restricted to those with a judged 6-month life span but rather is extended to those people able to live with their illness while

continuing to receive treatment but are clearly suffering financially because of their increasing debilitation.

- 4 The RCN would also caution that care is taken to consider any unintended consequences likely to emanate from a change in legal definition including potential implications for insurance policies, employment law, mortgages etc.

### **Background information**

Quantifying life expectancy in terminally ill patients is fraught with difficulties and if pushed to quantify clinicians are often 'proven wrong'. Many clinicians feel that a discussion with patients about their prognosis at an early stage including the issue of likely time to death with an associated parallel plan is more helpful. This should also include discussions about financial support, which can be a primary concern for people especially if they and/or their carers are having to give up work.

The current legal definition of terminal illness and the acceptance of the six month life expectancy was accepted as being fit for purpose at a time when it was commonplace for this to refer to people who in the main were dying from cancer. At that time there was not an appreciation of the other complex long-term degenerative conditions, which would also have rendered people terminally ill with less than six months to live. Additionally since the adoption of the current definition diagnostic and treatment advances have led to better and earlier diagnosis, treatment and prognosis resulting in many people living for longer periods of time with diagnosed debilitating disease.

This in itself has imposed severe financial difficulties for those people for longer periods of time.

The system in England at present is reliant on a clinician determining whether a person is likely to die in the next six months and completing the necessary forms to progress fast track access to benefits to support the individual financially in the last months of their life. Once benefits have been awarded, they remain in place until the person dies even if this exceeds six months. However, where a clinician judges that someone may live beyond the current 6-month rule, that individual, despite suffering severe hardship resulting from their illness does not have access to financial support.

For those with a life limiting illness, who have a clear six months prognosis, the current rules work well. However, where there is not a clear indication from the clinician as to how long someone might normally be expected to live, individuals have to resubmit an application without medical assessment or return to their consultant/doctor to request a clearer timeline. Both add more time to an individual experiencing financial hardship and adding more stress to an already stressful situation.

Some further points the RCN would add are:

1. The six months definition creates an inequality of access for people dying from non-malignant diseases where prognosis of likely time to death can be exceptionally difficult such as dementia and a range of neurological diseases.
2. The six months definition is helpful to some people with cancer but detrimental to others. Health and care professionals do tend to identify some diseases as having a short prognosis whilst forgetting to look at the "whole picture" for people with co-morbidity.

- The Care Quality Commission and the General Medical Council define End of Life Care as anyone with a probable prognosis of one year or less. The RCN believes that the twelve month timescale will still be problematic but recognises that regulators and professional bodies have a place to play in influencing the definitions.

## **Conclusion**

In conclusion the RCN believes that the term terminal is neither appropriate nor helpful when talking about life limiting illnesses or impending death. The RCN would suggest that 'in the last years of life' would be a more appropriate terminology. There are a number of illnesses, which will result in death but over a longer trajectory and those people and their families should have access to benefits in a timely way and not be subjected to additional burdensome assessment. The RCN welcomes the review and believes that the legislation should be updated to reflect the changes and advances that have occurred in diagnosis, prognosis and treatment since the legislation was put in place. This, however, should not be to the detriment of people who are facing an uncertain future nor be a covert way of reducing the demand on the benefits system.